



Advance Care Planning: Backgrounder

OMA's End-of-Life Care Strategy

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Definition/Legal Foundation

Advance care planning (ACP) is a process of considering, discussing and planning for future health care in the event the individual is incapable of consenting to treatment. It is based on the person's wishes, values and beliefs. The Ontario Medical Association (OMA) believes it is important that people make their end-of-life wishes known whatever they are. The evidence shows that patients' care preferences change over time and in accordance with their changing health status and personal circumstances.^{ab} This underscores the importance of viewing advance care planning as an ongoing process rather than directed toward a static plan.

Ontario's legislative framework for ACP, *The Health Care Consent Act*, favours contextualized patient decision-making and requires informed consent to treatment from a patient or his or her substitute decision-maker. Advance care planning helps to inform discussions between providers and the substitute decision-maker(s) at such time as consent is required for a specific treatment or a treatment plan. Advance care planning covers a range of activities including conversations about wishes for end of life care, appointment of a substitute decision maker through a Power of Attorney for Personal Care (POAPC) and advance directives (either as a stand-alone document or as part of a POAPC). In Ontario, advance directives do not "speak for" a person as is the case in many other jurisdictions. They help to inform the consent process for the substitute decision maker. The exception to this rule is the fact that a physician acting in an emergency situation where it is impossible to reach the substitute decision maker cannot administer treatment that she/he knows is contrary to a patient's capable wish.

The two key elements of advance care planning in Ontario are:

- Expression of wishes, values and beliefs about end of life care in the event the person becomes incapable; and
- Selection of one's proxy or substitute decision maker: the individual who will make health care decisions in the event the patient becomes incapable

Ideally, advance care planning is an ongoing process that supports people to consider (and re-consider) their care preferences in a realistic way and in the event of a number of likely scenarios.

Recognizing that advance care planning is rooted in local laws is important because it means that it is not always advisable to borrow forms from out of jurisdiction or for patients to rely on the same websites and tools that have guided their family or friends outside of Ontario.

^a T R Fried, A L Byers, W Gallo, P Van Ness, V R Towle and J R O'Leary, 'Prospective study of health status preferences and changes in preferences over time in older adults', *Arch Intern Med*, vol. 166, 2006, pp. 890–95.

^b P H Ditto, J A Jacobson, W D Smucker, J H Danks, and A Fagerlin, 'Context changes choices: a prospective study of the effects of hospitalization on life sustaining treatment preferences', *Med Decis Making*, vol. 26, 2006, pp. 313–22

Figure 1

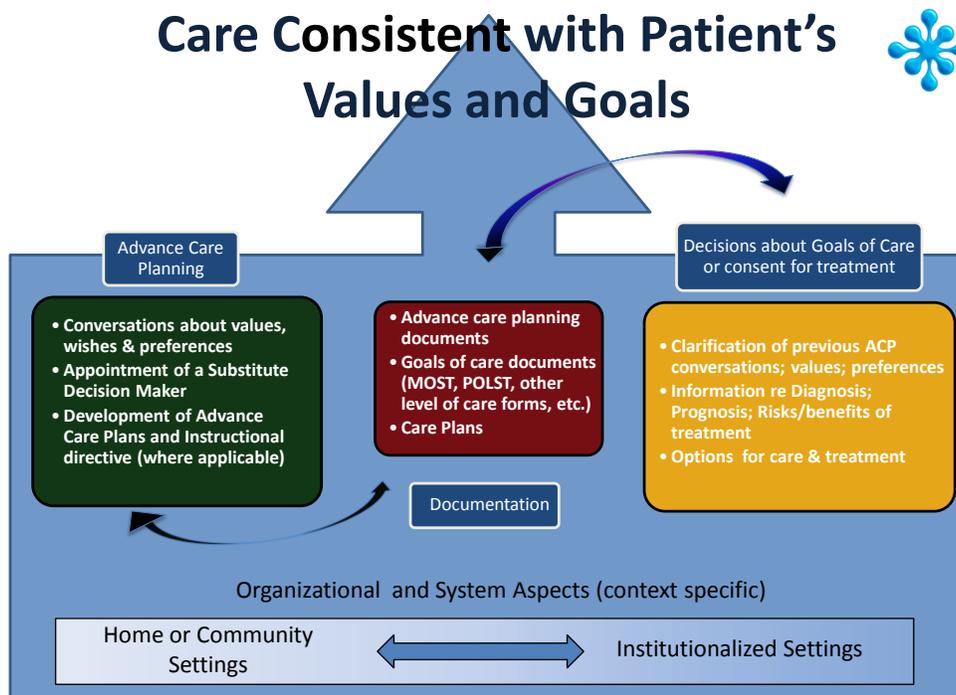


Figure 1 draws from the conceptual framework developed by the Canadian Researchers at the End of Life Network (CARENET), which broadly defines *end-of-life communication and decision-making* as a communication process that includes discussion of death and dying (e.g., as potential outcomes of treatment or illness progression). CARENET's conceptual framework also distinguishes three dynamic processes involved in Ontario's end-of-life communication and decision-making: 1) advance care planning, 2) goals-of-care designation and consent to treatment, and 3) documentation (Figure 1). The *HCCA* provides the conceptual and legal framework from the first consideration and expression of wishes to the individual treatment and care plan. .

Why Advanced Care Planning?

In 2011/12, Ontario had more than 96,000 deaths, representing more than 1/3 of all deaths in Canada. This represents a 33% increase in deaths over 2004. (Statistics Canada, 2012). In addition, two thirds will die with 2 or more chronic diseases after years of increasing frailty. (CARENET, 2012)

The proportion of the population aged over 65 years will continue to grow as baby-boomers age, with the first wave of boomers just hitting retirement age now. The number of seniors aged 65 and over in Ontario is projected to more than double from about 2.0 million, or 14.6 per cent of

population, in 2012 to almost 4.2 million, or 24.0 per cent, by 2036. The growth in the share and number of seniors will accelerate over the 2012–2031 period as baby boomers turn age 65.^c

Just as baby-boomers, with their desire for personal autonomy and individualism, were able to radically change medical practice around labour and birth boomers are likely to want more personal choices around their death and dying. However, to have their wishes carried out at end of life Ontarians need to become more familiar with advance care planning and the importance of legally appointing an SDM. Up to 70% of dying patients^d are not capable of decision-making and 42.5% of patients required decision making. The choice of an SDM is extremely important to ensure that person will act in the person's best interest and reflect his/her wishes.

A recent survey found that more than 80% of Canadians say they are comfortable talking about their end of life care and related issues.^e However the same survey shows only one-quarter of Canadians over age 30 have made end of life care plans and just over 40% of those over age 70 have done so. An earlier study^f found that:

- 86% of Canadians have not heard of advance care planning;
- Less than 50% have had a discussion with a family member or friend about their end of life care wishes;
- Only 9% of Canadians had ever spoken to a health care provider about their care at end of life;
- More than 80% do not have an advance directive or written plan;
- Only 46% have chosen a substitute-decision-maker (SDM).

Advanced care planning is a priority in the OMA's End of Life Strategy because research has shown that advanced care planning improves quality of life for both the patient and family members when expressed wishes are known and followed. Stress, anxiety and depression are significantly reduced.^g Other benefits include less aggressive and invasive interventions, decreased rates of hospital admission both in the 12 months before death and at time of death. Advanced care planning leads to increased rates of hospice admission where prior expressed wishes are respected and followed.^h Another study found the following benefits:

- Decreased ICU use; decreased chemotherapy
- Greater use of Hospice

^c Ontario Population Projections: Update. Ministry of Finance, Government of Ontario 2012

^d Silveira et al. NEJM 2011; 62:1211-1218

^e Environics research survey commissioned by St. Elizabeth, October 2013.

^f Ipsos Reid for CARENET, 2012

^g Detering KM, Hancock AD, Reade MC, et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ* 2010;340:c1345.

^h Abel J, Pring A, Rich A, Malik T, Verne J. The impact of advance care planning of place of death, a hospice retrospective cohort study. *BMJ Support Palliat Care* 2013;3:168-73.

- Caregivers had a perception of increased quality of life for the patient and, for themselves perceived less anxiety, depression or regret and they felt more prepared for the death.ⁱ

A 2008 systematic review of advanced care planning models concluded that research supports an approach to care planning that engages values, uses skilled facilitators and focuses on key decision-makers (patients, SDMs/caregivers and providers).^j Patients find the process itself helpful since it allays some of their basic fears, like becoming a burden on others, loss of independence and concern for self.^k

Summary

With less than 20% of Canadians aware of what the term advanced care planning means, it is clear that public awareness is key to an end of life strategy among the public, physicians, hospitals and other stakeholders who are well-placed to encourage thinking about and expressing one's end of life care wishes. The two key messages the OMA Strategy promotes are:

1. Talk to your loved ones and your physician about your wishes and values which inform your choices for end of life care.
2. Appoint a substitute-decision-maker through a Power of Attorney for Personal Care: the individual who will make your health care decisions in the event that you are unable to consent for yourself.

Quality of life at end of life is individual and contextual and can be enhanced if wishes and preferences are known. Ontario's *Health Care Consent Act* provides a framework for informed consent to treatment, development of an individualized end of life treatment plan and respect for values, wishes and beliefs in advanced care planning.

ⁱ Wright et al. *JAMA*; 2008;300:1665

^j Lorenz KA, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, et al. Evidence for improving palliative care at the end of life: a systematic review. *Ann Intern Med* 2008;148:147-59.

^k Levi BH, Dellasega C, Whitehead M, Green MJ. What influences individuals to engage in advance care planning? *Am J Hosp Palliat Care* 2010;27:306-12.